

Evaluation of the Family Action Small Steps Service

Final Report

June 2019

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Envoy Partnership is an advisor in evidence-based communications and strategic research. We specialise in measuring and demonstrating the value of social, economic and environmental impacts. Envoy Partnership is dedicated to providing organisations, stakeholders, investors and policy makers with the most holistic and robust evaluation tools with which to enhance their decision-making, performance management and operational practices.

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Executive Summary

The aim of the Small Steps Service is to provide early support and evidence-based interventions to families of children and young people displaying behaviour that causes concern or challenges: both for families where there is no formal diagnosis of ASD or ADHD, and for families that have had a diagnosis of ASD and/or ADHD. The service is subcontracted to Family Action through Nottinghamshire County Council and commissioned by the Healthy Families Programme contract. Small Steps operates by providing a range of services including Drop In sessions, workshops, one-to-one support, and an Information and Support Line.

Envoy Partnership were commissioned by Family Action to evaluate Small Steps. The evaluation sought to understand the effectiveness of the service, the outcomes created for stakeholders, and the impact of the service on the Concerning Behaviours Pathway.

Outcomes of the service

The evaluation showed significant outcomes for families. Most significant were the outcomes for parents and carers, including an **improved understanding of their child's behaviour**, feeling **less isolated** and **more confident**, and in some cases being **better able to manage their child's behaviour**. Sometimes this leads to **improved relationships between parents/carers and their children**.

The Small Steps Service has helped **improve the mental wellbeing of parents and carers**. This is because Small Steps gives them an opportunity to share their experiences, 'offload', and to be listened to. Parents who have used the service and are now discharged had an average increase of 5.6 points on the Warwick-Edinburgh Mental Wellbeing Scale, moving from 43.6 points to 49.2 points.

For some parents and carers, **the support they receive from school and from other services has improved** as a result of Small Steps' work. Parents and carers are also better equipped with **knowledge of other services** and where they can get further help if needed.

"I feel like I'm calmer, not shouting as much with [my granddaughter] as much as I used to. I feel like I understand the ADHD, the behaviour more. She hasn't had as many meltdowns so I think things are improving." [Carer]

"I get a sense of relief coming here. It gives me a chance to blurt out everything that's been building up – to offload. You get to speak to someone who listens and who understands." [Parent]

"Small Steps are a big support to me and my son. They have given me the confidence to deal with school and so many ideas on how to deal with my son on a day to day basis." [Parent]

"At one point before [I started with Small Steps] I rang social services in desperation: they came but said she [my daughter] didn't need their help – [I] didn't know where to go to get support. Small Steps helped me deal with the whole situation." [Parent]

Process evaluation

The process evaluation shows that the services offered by Small Steps work well overall; the content is appropriate, the staff are effective and empathetic, and many parents compared Small Steps favourably with other services. Both families and professionals commented on how Small Steps is able to give more time to individual families, giving families a greater level of consistency in support and thereby facilitating progress. However, there were a number of issues that were raised in the evaluation, which are outlined below.

Despite a lot of communication work by the Small Steps Service and its commissioners, not all partners were aware of the change to the pathway initially. At least one Early Help team was not aware of the new referral process until they tried to refer through a GP, and found out (some time after the change had taken place) that the advice they had been giving was wrong. There still appears to be some confusion among partners about exactly how the pathway works.

There is a significant delay between a family being referred and the Small Steps team having the capacity to progress this, driven in part by the very large numbers of referrals to the service. This means that it is taking some families longer to access support than might previously have been the case. This is a concern both to those who are referring to Small Steps, and the organisations that Small Steps refers on to.

“I still have significant concerns about the waiting times for referrals into our service from Small Steps, and families accessing post diagnosis support after we have made a diagnosis. I am concerned about the impact this is having on the children and their families. We have had less than 10 referrals into our service via Small Steps since August 2018 [as of mid-April 2019]. Compared to previous referral rate of 50-70 children per month.” [Partner – Paediatric services]

The delay is particularly problematic for those with significant needs who are likely to need to be referred on to a paediatrician. For children under five, there is a mechanism for partners to flag an individual case as particularly high need, and to ensure that the case goes directly to the GP for referral to a paediatrician. However, some partners believed that there was not a sufficient mechanism to fast-track referrals where, in the views of other professionals, a paediatrician will need to be involved, believing that, as Small Steps is now the main route for a family to be referred to a paediatrician, it now takes longer for families with significant needs to access paediatric support. This may be through a lack of understanding of the red flag referral possibilities that exist (including that partners believe that the red flag referral process is only for children under five), or because the children in question don't necessarily warrant a red flag but the partners believe they need to be fast tracked anyway.

The referral process can be time consuming. Some partners felt that it was disproportionately time consuming for those families that had lower levels of need. In addition, it can be particularly time consuming for schools to fill in the form when one of their students is exhibiting concerning behaviours at home rather than at school, and where they do not therefore have first-hand experience of the behaviours in question. The referral form has been part of the Concerning Behaviour Pathway for 10 years, however, so this is an issue that predates the Small Steps Service.

Conclusions

It is clear from conversations with other stakeholders that Small Steps fills a gap, delivering an important and necessary service that has positive outcomes for families.

Small Steps have already responded to many of the issues raised in this report, and their response is included in section 7.7. However, while some of the issues around the referral process and communication are the responsibility of Small Steps, many are not. **It is the recommendation of the evaluators that the issues identified need to be considered and reviewed within the context of a wider discussion about levels of demand and how the pathway is working in general.** If these issues are addressed then the service will have a very significant impact on families in Nottinghamshire.

1. Purpose of this report

This report shows the results of Envoy Partnership's evaluation of Family Action's Small Steps Service. It details the research undertaken, the data collected, the analysis, findings, and conclusions. The report describes the service's outcomes for different stakeholders, as well as the strengths of the service and the challenges it faces.

2. Evaluation objectives and methodology

2.1 Evaluation objectives

Envoy Partnership was commissioned by Family Action to evaluate the Small Steps Service. The evaluation aims were:

- To contribute to an evidence base around the model's effectiveness
- To examine the impact and effectiveness of the service for parents, children and young people and partner organisations
- To examine the impact of the service on families' emotional and mental wellbeing
- To examine the impact of the service on parents' understanding of their child's condition
- To examine the impact of the service on the Concerning Behaviours Pathway, and in particular the impact on referrals to paediatric services
- To inform future developments of the service
- To create a Theory of Change for the service together with the Family Action team

2.2 Evaluation methodology

Envoy Partnership's evaluation involved six stages of research, conducted between November 2018 and April 2019, as outlined in Figure 1. This included two phases of qualitative research, analysis of Family Action's quantitative data, and additional surveys with parents/carers.

Some changes were made to the original methodology, both at the start of the evaluation and during the evaluation, as the needs of the service and the level of access to stakeholders had changed.

1. In the first qualitative phase volunteer interviews were reallocated to the partners, as only two volunteers had started their roles.
2. A decision was taken to postpone the second qualitative phase, Phase 4. The original aim of this phase was to sense check earlier findings and the interpretation of the quantitative data. However, a number of process issues had arisen during the first qualitative phase, and it was decided that it would be more useful to use the second qualitative phase to explore whether these issues had been resolved. This required a delay in the fieldwork timings as many of the issues that were raised could not be have been resolved immediately.

Figure 1: The six research phases of the Small Steps Service evaluation

Stage	Objectives
1. Inception meeting and project setup	Review evaluation objectives, research plan, and key deliverables.
2. Qualitative Interviews Phase 1	Conduct interviews and focus groups with parents, children, and volunteers to understand what change arises, and how this change is created.
3. Quantitative research and analysis of Family Action data	Analyse the data that has been gathered by Family Action, including WEMWBS. Gather additional quantitative data by use of separate, reflective quantitative surveys to allow parents/carers to provide additional feedback beyond the scope of the monitoring data.
4. Qualitative research Phase 2	Conduct further qualitative research with stakeholders to sense check earlier findings and explore any issues in more depth.
5. Theory of Change Workshop, Development and write-up of draft Theory of Change	Develop the original Theory of Change model in an interactive workshop through use of the evaluation findings and together with key Family Action staff. <i>The Theory of Change is available in a separate report.</i>
6. Analysis and Report Writing	Analyse the qualitative and quantitative data and prepare a report for Family Action.

The quantitative research phase was made up of two parts: analysis of the data provided by Family Action, and development, distribution and analysis of an additional, reflective survey for parents and carers. The latter was informed by the findings of the first phase of qualitative research. However, the survey had a response rate of only six, even after extending the deadline.

Figure 2 shows the planned and achieved qualitative research sample sizes. Fewer parents and carers participated in an interview or focus group than planned. When the team conducted the initial research, relatively few parents had started using the Small Steps Service; turn out for the focus groups and consent for phone interviews was low as a result. The team did manage to talk to three children and two volunteers who all came along to one of the focus groups.

Figure 2: Sample Sizes for Phases 1 and 2 of the Qualitative Research

		Phase 1		Phase 2	
		Planned	Actual	Planned	Actual
Partners	Interviews	10 (5 ¹)	8	-	5
Parents and carers	Focus groups	3 focus groups	3 focus groups (8 people)	1 focus group	7 one-to-one interviews
	Interviews	10	1	-	-
Children	Face-to-face interviews or focus group	No specific target	3	-	-
Volunteers	Interviews	0 (5 ²)	2	5	-
Total		20 + 3 focus groups	22	5 + 1 focus group	12

¹ Originally five partner and five volunteer interviews were planned. However, volunteer interviews were reallocated to the partners as few volunteers had started their role.

² As above

3. About the Small Steps Service

The aim of the Small Steps Service is to provide early support and evidence-based interventions to families of children and young people displaying behaviour that causes concern or challenges, where there is no formal diagnosis of ASD and/or ADHD, but where behaviours may be indicative or characteristic of these conditions. Post-diagnosis support for these conditions is also provided. The service is subcontracted to Family Action through Nottinghamshire County Council and commissioned by the Healthy Families Programme contract.

The original Small Steps service ran as a pilot from June 2017 in Mansfield district only, with a focus on post diagnosis support. The specification was revised following Local Authority mapping of provision and gaps, and the current revised model has been delivered countywide since August 2018. The service currently employs 13 staff.

The service aims to fill a gap in service provision; it aims to be an innovative new service that will improve the lives of families who are facing uncertainty. It aims to facilitate early intervention approaches, information gathering, observations of children demonstrating symptoms of ASD and/or ADHD, and appropriate and timely input to specialist neurodevelopmental assessments for ASD and/or ADHD, including transition to adulthood and/or adult services as appropriate. It seeks to coordinate involvement between different agencies (schools, universal services, CAMHS, paediatrics, the Local Authority and voluntary sector) and promotes partnership working with parents/carers and children and young people (CYP) to give them the skills to manage behaviours and ensure good outcomes.

The service aims to deliver the following outcomes for children and young people:

- Support school readiness and transition between education settings
- Promote resilience and emotional wellbeing (for parents/carers and CYP)
- Manage risk and reduce potential harm
- Improve lifestyles for children, young people and families
- Maximise learning and achievement for CYP
- Support complex and additional health and wellbeing needs
- Ensure care planning and support delivered is child and young person centred

In addition, the service aspires to support the following system-based outcomes:

- Develop and maintain positive relationships with universal services (e.g. schools, Healthy Families Teams) and specialist services (e.g. community paediatricians, CAMHS, and the Family Service provided by the Local Authority)
- Ensure referrals made to specialist services are timely, appropriate and contain the information required
- Maintain continuity of care for children, young people and families who are going through a specialist neurodevelopmental assessment process

3.1 Accessing the Small Steps Service

The Small Steps Service is available to all families who live within the boundaries of the six Nottinghamshire Clinical Commissioning Groups (CCGs): Bassetlaw, Mansfield and Ashfield, Newark and Sherwood,

Nottingham North and East, Nottingham West, and Rushcliffe. Families are also eligible if their child attends an education setting or a GP within Nottinghamshire Local Authority boundaries.³

Families need to be referred before they can access the Small Steps Service, except for the Information and Support telephone line and the monthly Parent/Carers Drop In service, which can be accessed without a referral or appointment so that there is always some support available for families regardless of their place in the referral process. Referrals can come from different sources including, but not limited to, paediatricians, GPs, schools, the Healthy Families Team and the Local Authority. A form needs to be filled in by the referral party, giving demographic information and explaining the reason(s) for the referral. The form is known as the 'Getting to Know Me' (GTKM) form. Referrals can only be assessed once all information on the referral form is complete. If the referral is accepted, families will be put on the waiting list for the service(s) they would like to access, and can access the telephone line and drop in sessions in the meantime.

3.2 Types of services

The Small Steps team delivers a range of services for parents and carers and their children across different locations in the county. The services are set out below.

Information and Support Line

A helpline accessible to anyone who needs support or advice, including parents with a child with or without a diagnosis, schools or professionals. The latter mainly use the support line if they need information on the service or how to refer into it. The support line is accessible from Monday to Friday from 10am-2pm and is staffed by everyone in the Small Steps team, except volunteers.

Parent/carers Drop In Groups

Parents and carers can access monthly Drop Ins if they have concerns about their child's behaviour but no formal diagnosis. Parents of children with a diagnosis are also able to attend. They receive peer support from other parents in similar situations, and can share experiences and ideas. Groups are facilitated by members of the Small Steps team, alongside support from volunteers, and are held monthly in each of the CCG areas. No referral is needed to attend.

Four-week workshop series

Parents and carers of a child who displays behaviour that may be indicative or characteristic of ASD or ADHD, but have no diagnosis yet, can access the evidence-based four-week workshop series provided by the Small Steps Service. They learn about ADHD and ASD during the sessions, and are taught about evidence-based interventions such as play-based strategies, behaviour management, and support around parent-child relationships/interactions. The workshop content was designed by the Small Steps team.

Support from a specialist/senior practitioner

If parents have gone through the four-week workshop course, but there is a clear need for more support, they can be referred on to a specialist/senior practitioner. The specialist/senior practitioner will assess children where there are concerning behaviours indicative of ADHD/ASD to determine if an onward referral to Tier three services, such as a paediatrician or CAMHS, is necessary. Where a referral is required, these practitioners support families with the referral processes, coordination of information gathering and

³ There were two cases from families living in Nottingham City, and two cases from families living in Hardwick in Derbyshire.

recording of observations to facilitate the work of the Tier three services. Support is usually provided at the family's home, or during a clinic appointment.

One-to-one support from a Family Support Worker

Families with a child with a diagnosis can receive one-to-one help from skilled Family Support Workers who work collaboratively with the children and young people and parents and carers. They assist parent so work with their children to reach clearly defined outcomes, both at home and in school/community settings, and support parents with behaviour strategies and building parents' resilience and wellbeing. Sessions tend to take place at home, although some take place at school, as the focus is on supporting parents to be able to manage concerning behaviours.

Clinics/workshops

The Small Steps Service also offers a range of short-term, more specialised programmes for parents and carers with a child who has a diagnosis of ADHD and/or ASD. Currently there are workshops focussing on Sleep and Toileting.

New Forest Parenting Programme

The New Forest Parenting Programme is delivered over seven weeks for parents whose children (aged 3-12) have a diagnosis or behaviours indicative of ADHD.

Cygnnet Parenting Programme

This course further informs parents/carers whose children (aged 5-18) have a diagnosis of ASD and provides them with more strategies and tips.

One-to-one support from a volunteer befriender

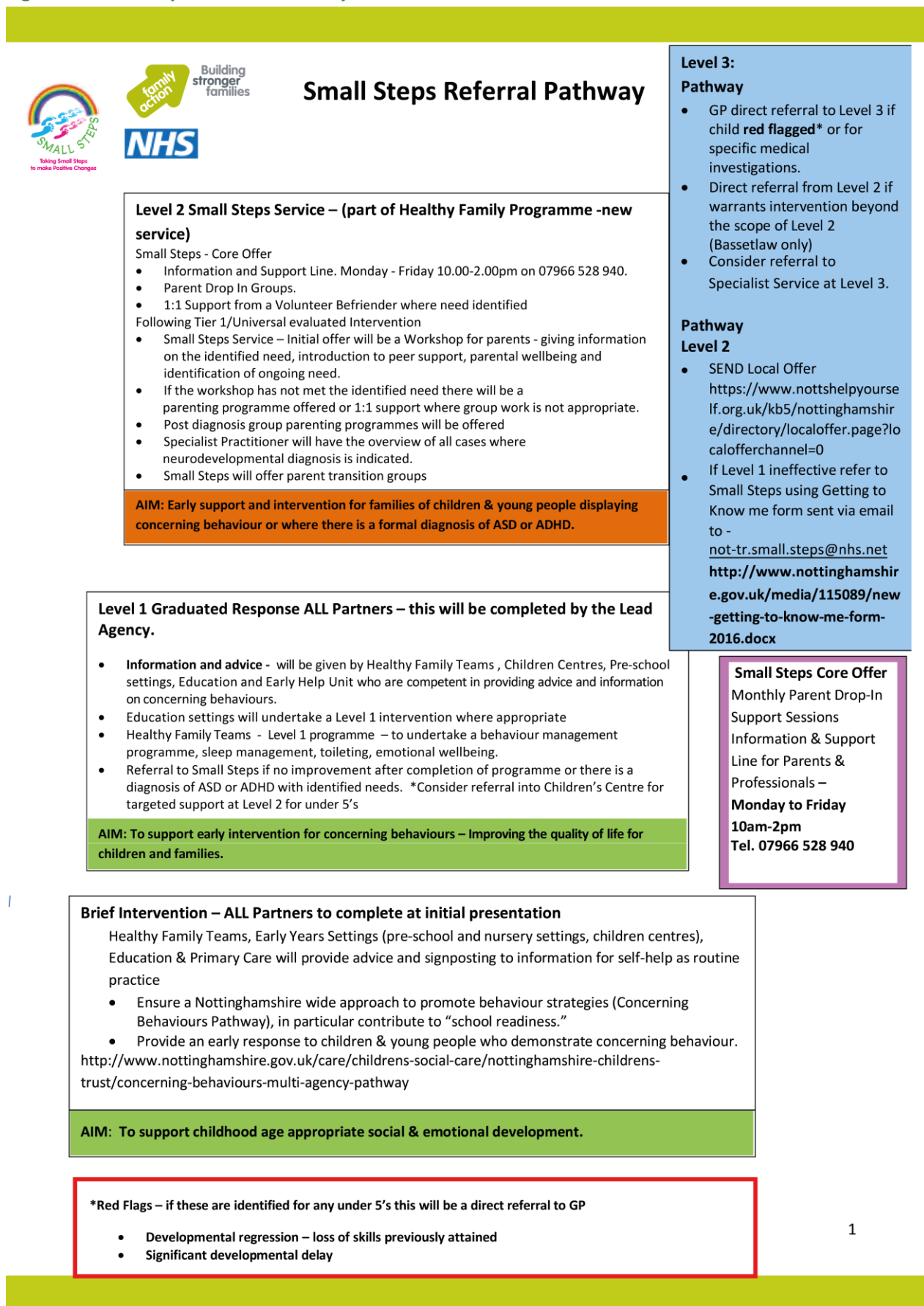
If a need has been identified for more (social) support, parents/carers can be matched with a volunteer befriender. Befrienders meet the parent/carer on a one-to-one basis at times and locations that work well for both parties. Many befrienders have first-hand experience of children with ADHD and/or ASD and can therefore provide peer support. Once parents and carers feel that they have made progress towards improving their situation, they can also become a volunteer befriender or volunteer to support parenting programmes and drop ins.

3.3 Changes to the Concerning Behaviours Pathway

The introduction of the Small Steps Service across Nottinghamshire was part of a recent change in the county's Concerning Behaviours Pathway. Parents and carers now need to go through the Small Steps Service before they can see a paediatrician. They are referred to the four-week workshop course and can receive other support from Small Steps. If further support is deemed necessary, they will then receive support from a specialist/senior practitioner who will support them in being referred to the Tier three services. Figure 3 shows the referral pathway in more detail.

This change to the referral pathway is intended to reduce pressure on paediatricians by speeding up the diagnosis process to support early diagnosis of ADHD and ASD, as well as avoiding unnecessary referrals. However, GPs are still able to refer a child who is under five years old directly to a paediatrician if they believe there is a medical, developmental or other need which makes an immediate referral vital (see 'Red Flags' in Figure 3).

Figure 3: Small Steps Referral Pathway



4. Service Outputs

Between the 1st of August 2018 and the 1st of May 2019, a total of 2,098 children were referred to the Small Steps Service. Due to the high volume of referrals, the team was only able to process and record about half (989 referrals) by the end of March 2019. **The output data below is based on these 989 recorded referrals.**

Half of the referrals to the service came from paediatricians. About a fifth of referrals came via the Healthy Families team (22%) and another fifth came via education/schools (20%). Only about 6% of referrals came via the Local Authority, and 3% via other sources, which included GPs and CAMHS.

Figure 4 shows the status of the referral by the different referral sources. A total of 806 children and young people (82% of referrals) were accepted to the Small Steps Service. Paediatricians had a much higher referral acceptance rate (95%) than the Local Authority (71%), Schools (68%) or the Healthy Family Teams (67%). The main reason for declining referrals was missing information (13%).

The higher acceptance rate for referrals from paediatricians may be partly because they are referring post-diagnosis, and as a result it may be easier for paediatricians to provide the necessary information. The acceptance rates are further discussed on page 25.

Figure 4: Referral status by source of referral

Referral status	Paediatricians		Healthy Families Team		Education/School		Local Authority		Other		Total referrals by status	
	Number	%	Number	%	Number	%	Number	%	Number	%	Number	%
Accepted	466	95%	145	67%	134	68%	41	71%	20	69%	806	82%
Declined: missing information	2	0%	54	25%	55	28%	9	16%	5	21%	126	13%
Declined: no further action	15	3%	9	4%	3	2%	6	10%	1	7%	35	4%
Other ⁴	6	1%	7	3%	5	3%	2	3%	1	3%	21	2%
Total	489	100%	215	100%	197	100%	58	100%	29	100%	988	100%

Figure 5 shows the age of the children and young people who were referred to the Small Steps Service, and of those who were accepted. Most children (about 60 percent) were between 6 and 11 years old.

Referrals to the Small Steps Service show a gender bias, with males making up almost three quarters of all referrals, as shown in Figure 6. The same can be said for the percentage of referrals that got accepted. Many studies show that males are likelier to have ASD than females, with some saying males are five times likelier

⁴ Declined and referred for Tier 1 intervention, On hold, and Signposted to other services

to have ASD than females, although these ratios vary widely across studies (Elsabbagh et al. 2011).⁵ Males are also six times likelier to have ADHD (Nøvik et al. 2006).⁶ Females were thus – compared to these averages – likely overrepresented in the referrals, as about one in three referrals were for females.

Figure 5: Age of referred and accepted children

Age	Referred to Small Steps		Accepted by Small Steps	
	Number of cases	Percentage of cases	Number of cases	Percentage of cases
0-5	183	19%	145	18%
6-11	595	60%	497	62%
12-16	201	20%	155	19%
17-19	10	1%	9	1%
Total	989	100%	806	100%

Figure 6: Gender of referred and accepted children

Gender	Referred to Small Steps		Accepted by Small Steps	
	Number of cases	Percentage of cases	Number of cases	Percentage of cases
Female	256	26%	207	26%
Male	732	74%	598	74%
Do not wish to disclose	1	<1%	1	<1%
Total	989	100%	806	100%

The service was running in Mansfield & Ashfield CCG before it expanded to the rest of the county. This is reflected in the referrals; the more established nature of the service in Mansfield & Ashfield has meant that it has seen more referrals than any other area (Figure 7).

Figure 7: Referral CCG

Originating CCG area	Number of cases	Percentage of cases
Mansfield & Ashfield	424	43%
Newark & Sherwood	280	28%
Nottingham North & East	92	9%
Rushcliffe	79	7%
Nottingham West	69	8%
Bassetlaw	41	4%
Hardwick*	2	<1%
Nottingham City*	2	<1%

*these areas are not usually covered by the Small Steps Service, except where a family attends an education setting GP in one of the other six CCG areas

The main reason for being referred to the Small Steps Service was Post ASD/ADHD diagnosis support, at 48% (see Figure 8). This is partly because such a high proportion of referrals so far are from paediatricians. The

⁵ Elsabbagh, M., Divan, G., Koh, Y. J., Kim, Y. S., Kauchali, S., Marcín, C., ... Fombonne, E. (2012). Global prevalence of autism and other pervasive developmental disorders. *Autism research: official journal of the International Society for Autism Research*, 5(3), 160–179. doi:10.1002/aur.239

⁶ Nøvik TS, Hervas A, Ralston SJ, et al. (2006). Influence of gender on attention-deficit/hyperactivity disorder in Europe. *ADORE. Eur Child Adolescence Psychiatry*; 15(Suppl 1): I15-I24 <https://adhd-institute.com/burden-of-adhd/epidemiology/gender/>

second most important reason (38%) was behaviour indicative of ASD/ADHD whilst no formal assessment or diagnosis of ASD and/or ADHD had been made.

The proportion of referrals for children without a formal assessment or diagnosis increased over time, as could be expected by the change in the referral pathway which meant families now have to go through Small Steps before they can be referred to a paediatrician. This is thus likely to increase even further as a proportion of the total in future.

The reason for referral is unclear in 13% of referrals. This is sometimes due to missing information: children might have a diagnosis but this has not been stated on the referral form. However, in most of these cases the information that is provided does not give strong enough evidence that the child's behaviour is indicative of ASD/ADHD. These referrals are therefore most likely to be declined.

Figure 8: Reason for referral by source of referral

Referral status	Paediatricians		Healthy Families Team		Education/School		Other		Total referrals by status	
	Number	%	Number	%	Number	%	Number	%	Number	%
Post ASD/ADHD diagnosis support	354	72%	38	18%	33	17%	46	53%	471	48%
Behaviour indicative of ASD/ADHD but no formal assessment /diagnosis	105	21%	128	60%	122	62%	24	28%	379	38%
Unclear at referral	25	5%	47	22%	42	21%	13	15%	127	13%
Re-referral for additional support	6	1%	2	1%	0	0%	4	5%	12	1%
Total referrals by source	490	100%	215	100%	197	100%	87	100%	989	100%

Figure 9 shows the usage of the different Small Steps services. Drop Ins were the most highly attended, with 235 parents and carers attending. Many parents and carers use it as a first step to getting referred into the service. Workshop attendance (17%) was also high, even though these only started running in October. A considerable number of parents and carers (75) also received one-to-one support.

The Cygnet and New Forest Parenting Programmes both only started running from February 2019, as the Small Steps team was unable to access the training for the programmes until January 2019.

Figure 9: Number of users per service

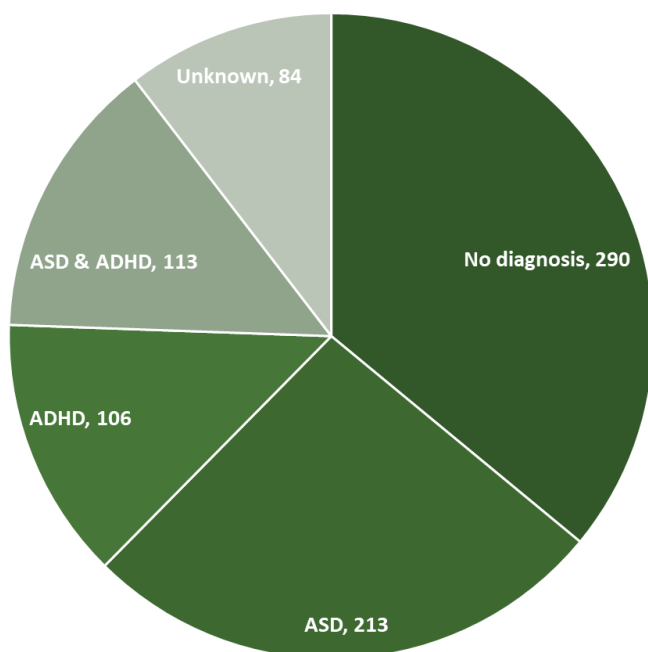
Service	Number of users	Percentage of cases
Drop ins	235	52%
Workshops	79	17%
One-to-one support	75	17%
Cygnets Parenting Programme	25	6%
Sleep clinic	17	4%
Toileting clinic	16	4%
New Forest Parenting Programme	7	2%
Total	454	100%

As of March 2019, there were 482 families whose referral to Small Steps has been processed, but who were on a waiting list for the service. The breakdown of the services they are waiting for is as follows:

- Specialist Practitioner – 126
- Family Support Worker – 7
- Parenting programmes/workshops – 349

As the parenting programmes/workshops are aimed at families without a diagnosis, this support having the highest waiting list is not surprising; Figure 10 shows that 290 children who were accepted to the service did not have a diagnosis yet, with a further 84 ‘unknown’, who are therefore unlikely to have a diagnosis either.

Figure 10: Diagnosis of children who are accepted to the Small Steps Service



The support line is accessible to both professionals and parents and carers, who have made consistent use of this service. Figure 11 shows that a total of 802 people called the support line from August onwards, with a steady number of calls, apart from fewer calls in August and a clear drop in December. Almost 60% of calls were made by professionals.

Figure 11: Calls to the Information and Support Line

Month	Professionals		Parents and carers		Total calls	
	Number of calls	Percentage calls	Number of calls	Percentage calls	Number of calls	Percentage calls
August	39	8%	23	7%	62	8%
September	48	10%	36	11%	84	10%
October	88	19%	35	10%	123	15%
November	82	18%	58	17%	140	17%
December	45	10%	23	7%	68	8%
January 2019*	50	11%	55	16%	105	13%
From 24 January until 31 March	115	25%	105	31%	220	27%
Total	467	100%	335	100%	802	100%

* Due to a change in data collection, the month of January only includes calls up to and including the 23rd of January. For the same reason, the data until the 31st March is not split out

A total of 141 cases have already been closed/discharged (Figure 12). 27% were closed without a formal diagnosis, which signals that the service might already be avoiding unnecessary referrals to paediatricians.

About 30% of all cases were closed due to non-engagement. In 72% of these cases the child has had a diagnosis, so this could be the reason for non-engagement.

Figure 12: Closures/discharges and diagnosis status

	Total closures/discharges		Intervention complete/support no longer needed		Non-engagement	
	Number of cases	% of cases	Number of cases	% of cases	Number of cases	% of cases
Closed Post Diagnosis	94	67%	63	64%	31	72%
Closed where there is no formal ASD or ADHD diagnosis	47	33%	35	36%	12	28%
Total	141	100%	98	100%	43	100%

5. Outcomes

A number of outcomes were identified during the research. Some of these had already been identified in the service's existing Theory of Change, and others were new outcomes that were described by stakeholders. These outcomes are discussed below.

Most of the findings in this section are drawn from the focus groups and one-to-one interviews with parents and carers (collectively referred to as 'interviews' below). However this section also references data from the survey of parents and carers. This survey data can be found in Appendix 2 and Appendix 3.

Improved understanding of child's behaviour and supported parents to manage their child's behaviour

The interviews with parents suggest that the **improved understanding of their child's behaviour** is one of the clearest benefits of the Small Steps Service. This was due to the support of the Family Support Workers during the workshops and one-to-one work, the content of the workshops, and the opportunity to share experiences with other parents. The survey supported this; three out of six parents said they 'strongly agree' that they have a better understanding of their child's behaviour.

"I get ideas for what to do to help with behaviour. For example, I got help on adapting a rewards chart so that it's suitable for someone of my son's age. My daughter uses it now too so she doesn't feel left out." [Parent]

"I feel like I understand my granddaughter's behaviour a bit. She had a bit of meltdown when she went back to school after half term and I thought to myself 'how did you feel when you had a holiday and had to go back to work?' " [Carer]

"It helps empathise with the child; quite a lot of details from the presentation were from a child-centred perspective and that was quite helpful and you can empathise with them more. Rather than seeing your role as a chief nagger, you know you are their champion and you can take their side." [Parent]

Some parents described in the interviews how they are also **able to better manage their child's behaviour**, partly because of this greater understanding of their behaviour, and also because they are given strategies and practical solutions. In the survey, one parent (out of six) said they 'strongly agree' and two said that they 'somewhat agree' that they are better able to manage behaviour.

"I wouldn't have had so much knowledge on ASD without the course. A worker came to school and I also got referred to another nine-week course which was really useful. I better understand now that it [issues with child] is not about what I thought it was about. [As a result], I can better deal with behaviour." [Parent]

"I feel like I'm calmer, not shouting as much with [my granddaughter] as much as I used to. I feel like I understand the ADHD, the behaviour more. She hasn't had as many meltdowns so I think things are improving." [Carer]

"[The service] helped [me] to take a step back instead of immediately reacting to behaviour of my son." [Parent]

The interviews also highlighted how some parents were more confident generally, and in particular how they were more **confident in their parenting** ability, and more able to **'stay calm' when things go wrong**. Often this was because they had the opportunity to discuss their child's condition with other parents and

professionals who understood their situation, and realised that other families had the same experiences and that the challenging behaviour was not due to poor parenting on their part.

In the survey, one parent strongly agreed and two somewhat agreed that they felt more confident in their parenting ability, and two parents said they 'strongly agree' and a further parent said they 'somewhat agree' that they are able to 'stay calm' when things go wrong.

"At one point before [I started with Small Steps] I rang social services in desperation: they came but said she [my daughter] didn't need their help – [I] didn't know where to go to get support. Small Steps helped me deal with the whole situation." [Parent]

Improved mental wellbeing of parents and children

The Small Steps Service appears to have helped improve the mental wellbeing of parents and carers, mainly because they are better able to understand their child's behaviour, and in some cases they are also able to manage their child's behaviour better. This greater understanding of the behaviour means that it sometimes has less negative affect on the parents.

The support provided by Small Steps can also give parents and carers a chance to share their experiences with someone who understands (both the Small Steps team and other professionals) and gives them reassurance and an opportunity to 'offload'.

"I get a sense of relief coming here. It gives me a chance to blurt out everything that's been building up – to offload. You get to speak to someone who listens and who understands." [Parent]

"I still get tips from people, and reassurance. It's helpful to keep coming because as he gets older you get new things to deal with. It's also nice to meet people on the same road as me." [Parent]

"The fact they [families] can go to different drop in facilities is very useful. It's fabulous that families get together with similar needs and get a bit of reassurance. They can also build up some contacts for themselves as families." [Partner – Early Help Team]

Parents especially talked about increased confidence, being more calm, and being able to take a step back and reflect.

"It's called Small Steps and I think that you can't expect more than just a shift, but I also think I feel more confident and perhaps I don't care so much what other people think." [Parent]

In the survey, one parent strongly agreed (out of six) and two somewhat agreed that they felt more positive about themselves, and that their mental health and/or well-being had improved.

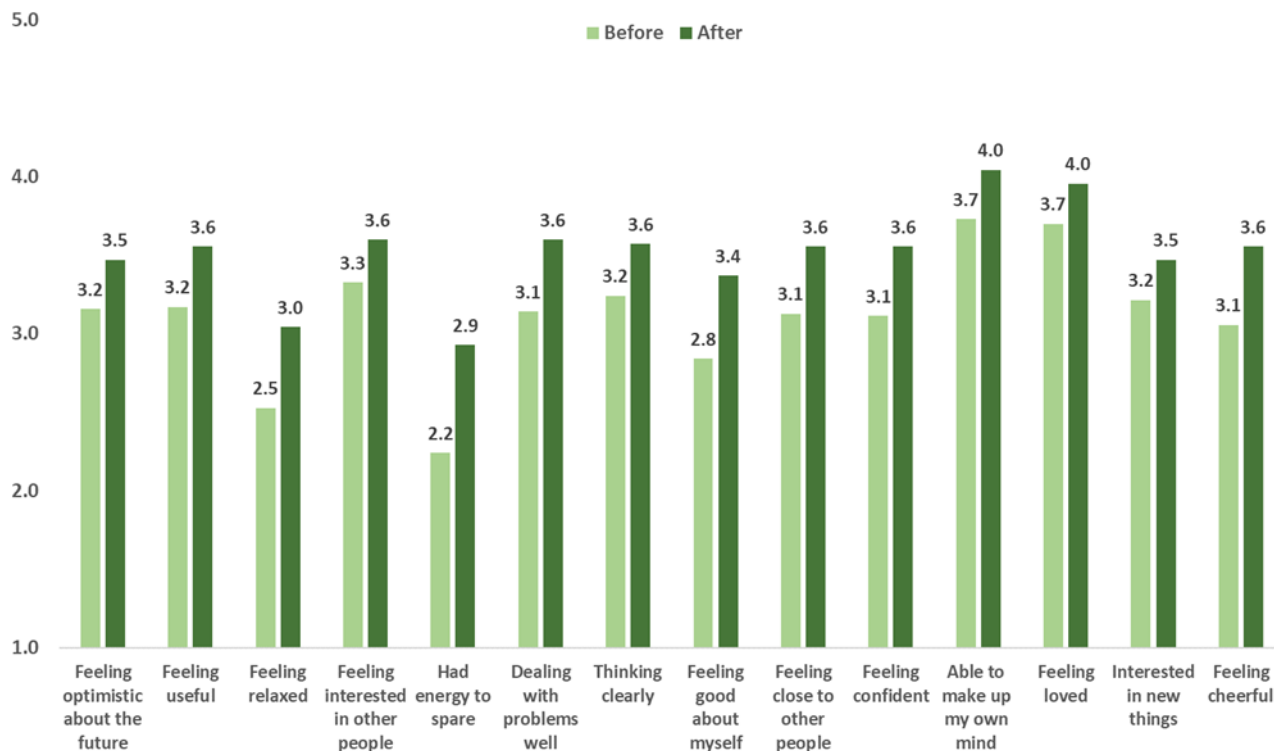
Small Steps' data on well-being also shows a positive picture. Parents (n=70) who have used the service and are now discharged had an average increase of 5.6 points on the Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS), moving from 43.6 points to 49.2 points.⁷ As shown in Figure 13, increases were witnessed on each of the 14 measures, with the largest increase being for 'had energy to spare'.

There is some evidence that the mental wellbeing of children has also improved; some parents and carers described positive changes for their children. However, these changes are not universal; for many parents

⁷ WEMWBS is a 14 item scale with five response categories, giving a score of between 14 and 70. In UK population samples, the bottom 15% of scores are from 14-42%

and carers, the main change in mental wellbeing was for themselves, with no clear evidence of any change for their children.

Figure 13: Before and After WEMWBS scores of parents (n=70)



Reduced social isolation

Some parents have experienced a reduction in social isolation. For most parents, the workshops have only recently started and some have low numbers of people attending. Peer support opportunities have not yet been fully developed. However, parents have still found the opportunity to share experiences useful and have benefitted from knowing that they are not alone in the challenges they are facing. In the survey, two parents (out of six) strongly agreed and one agreed that they felt less isolated.

“I feel less isolated and out of control and her [Support Worker] professionalism and care have been vital for me.” [Parent]

In addition, the Small Steps team members have been able to give significant amounts of time and support, and this has helped parents feel less isolated. Parents also did not feel like they were being looked down on, unlike at some other services.

“I went to an ADHD support group, for which funding has now been stopped. I’ve been on a [different] course but I think I enjoyed this more, partly because it was a smaller group and focused more on the needs. It’s interesting to hear how all the parents cope and to know you’re not alone in this situation.” [Parent]

“The course was really useful for signposting to other services and learning from other parents e.g. strategies, sharing ideas and experiences.” [Parent]

Improved relationship between parents and children

In the interviews, some parents and carers discussed how the Small Steps Service has helped improve their relationship with their child. However, the nature of this relationship can be affected by the child's autism and/or ADHD, and this was not the case for all parents and carers. This is reflected in the survey, where one parent strongly agreed (out of six) and one agreed that their relationship with their child/children had improved. However, two somewhat disagreed and one strongly disagreed.

When relationships do improve, this is often because parents know better how to interact with their children and, due to better handling of their behaviour, their children had fewer meltdowns.

“Small Steps made the difference between having no relationship and having a relationship with my son. Due to the support I could see that the issue was at school and not at home, but that he would take this home and that that resulted in problems at home. I could see that thanks to the service.” [Parent]

“Small Steps has still helped, I've learned different ways to connect with my son: he's very much on his own a lot, and we now schedule some 'us' time before he goes to bed. That impacts the family life too, as it helps with the atmosphere in the family.” [Parent]

Increased awareness of local provision for families affected by autism and/or ADHD

Some parents spoke about how they were more aware of services and support that is available for families affected by autism and/or ADHD. Two of the six parents who took the survey strongly agreed, and one somewhat agreed, that they are more aware of local provision.

“I have been referred to the drop-ins and was signposted to other services, e.g. CASY [Counselling and Support for Young People], a local service doing counselling, which was something I was interested in.” [Parent]

One parent spoke about how conversations with other parents and professionals at Small Steps helped them decide about medication options for their son.

“We had a really difficult choice to make about the ADHD diagnosis and whether to go down the medication route. My husband was against it at first – we might be putting him on drugs that he'll need to take for years and years. So it was helpful to come here and talk to other people and get an idea about their views. You have to make this big decision that you're not prepared for. We decided to go with the medication in the end – but we had the opportunity to work out what we wanted to do.” [Parent]

Improved support from school

In the qualitative research, a number of people spoke about how the support that they received from their child's school has improved. However, this wasn't reflected in the survey, where only one of the six parents said that the support that they received from the school had improved. When support from school did improve, this might be because the parent or carer is more aware of what they are entitled to, and it may be because a member of the Small Steps team has acted as an advocate on their behalf.

“The support worker got things sorted out... She acted as a sort of solicitor at school – stood up for my daughter and her rights.” [Parent]

“The support worker connected really well with my daughter and that helped a lot. Got the family on the right track, especially with regards to school situation. That was a real issue. My daughter [is] now back in education at college.” [Parent]

“Some families are scared to engage with schools – they don't know how to negotiate. It's not about telling them – the parent – it's about encouraging them and helping them negotiating.”
[Partner – Early Help]

“I found out a few things about what I can expect because my son has got an EHC plan and I didn't realise the frequency of meetings that we were entitled to at the school and should be making use of. So that was something concrete I took away from the sessions.” [Parent]

“Small Steps are a big support to me and my son. They have given me the confidence to deal with school and so many ideas on how to deal with my son on a day to day basis.” [Parent]

Reduced inappropriate referrals to paediatricians and reduce number of follow up appointments

The Small Steps Service has been part of, and has contributed to, a change in the referral process that has taken place for children and young people who present concerning behaviours.

This change is intended to reduce inappropriate referrals to paediatricians and to reduce follow up appointments. Feedback from partners suggests that this has already occurred to some extent, and that it has the potential to do so further in the future, although there are a variety of issues that have arisen with the change in referral process. This is discussed further in the *Process Evaluation* section below.

Improved self-esteem and future employment opportunities for volunteers

Improved self-esteem and future employment opportunities for volunteers was one of the expected outcomes of the service. However it is too early to judge this outcome fully; very few volunteers had started in their role during the research. Some parents were unaware of the befriending component, and what this meant. Those volunteers who had started spoke positively of the experience.

“There was a lady sitting in the room who was a befriender but she didn't really speak so I don't know what sort of thing she does.” [Parent]

“[On befriending] someone came last week [when person wasn't in] to tell us a little bit about becoming a befriender but no one asked if we wanted a befriender.” [Carer]

“[My motivations for becoming a befriender were] I wanted to gain more experience working with children with ADHD/ASD, learning about it, looking for skills and knowledge. I heard about Small Steps from a friend who had a leaflet, I called them up to see if they had volunteering places.”
[Volunteer]

“[As a volunteer] I only did one visit on my own but felt that made a difference – it went really well. I made a difference to her too – [it] was rewarding. [I] can't say if the family already has improvements in behaviour – it's too early.” [Volunteer]

Partners' views on impact on families

Most partners who were interviewed felt it was too early for them to offer a judgement on the impact that Small Steps was creating for families. Some partners had no information to enable them to make a judgement; others had received indirect feedback, but nothing more. Where partners did have a view on the impact for families, it was very positive, as illustrated by the following quote:

“I had one family whereby a young boy, wouldn't leave his bedroom, had had a bereavement, his dad had died and he had also been diagnosed with ASD. He became withdrawn, wouldn't leave [his] bedroom. The school didn't know what to do. Lots of support had been given, quite a few referrals made, the Small Steps referral was made by [his] school...” [The Small Steps project]

worker] was allocated to work with the family. He went out, and he had a number of sessions when he could work with mum and try to engage. [Small Steps] often did extra visits as the boy was hard to engage, he wouldn't speak. But by end of the interventions on a number of occasions [they were] successful in getting him to leave the home. [The Small Steps project worker] would liaise with myself and with CAMHS, he was really successful at supporting mum, getting her to try different strategies, take on board different advice given by CAMHS and the Family Support intensive worker, and would then work with different families and feedback at meetings.” [Partner – Early Help Team]

6. Case Study one: Robbie

Robbie* has a diagnosis of ADHD and was 13 years old when he was referred to Small Steps by his Paediatrician for support around emotional health, parental advice and support. Robbie lives at home with his mum, Helen and three younger step-siblings. Robbie has not had contact with his father since he was three years old, and his step-father left the home two years ago. Although his step-father has contact with the three younger children, he does not want to have contact with Robbie. Robbie has a positive relationship with his maternal grandparents who he visits regularly, but his relationship with Helen is turbulent.

Support from CAMHS and the Youth Offending Team was provided to Robbie due to incidents both in the home and community where Police were contacted as a result of Robbie's behaviour (threatening behaviour and public damage). However, Robbie did not engage with either service. Robbie finds school difficult and has faced a number of exclusions. The school does support Robbie by providing 1:1 time fortnightly. Furthermore, Robbie attends homework club and has a green card which he can use when he requires time out from lessons if he feels overloaded. Medication was not effective as Robbie did not eat, and he was therefore unable to keep his weight up which was necessary for the medication to be used.

Approach

Family Action formed a Support Plan following home visits with both Helen and Robbie's maternal grandmother to identify how Robbie and his family could be best supported. Small Steps reflected on the environment in which Robbie lives and why he may have a more positive relationship with his maternal grandmother. He lives with three younger siblings who also receive attention from his mother, and often the attention which Robbie receives is negative as a result of his behaviour. Support was provided to Helen around routines, relationships and positive activities for Robbie. Small Steps agreed to put in place two active support sessions with a male support worker. The aim of this would be to provide support from a male role model, engage with Robbie through activity, rather than sit-down support, and encourage involvement in a hobby which would offer more positive activity long-term. Another Small Steps team worker also worked with Helen around routines to ensure that she gets 1:1 time with Robbie to promote positive behaviour, and monitored parental wellbeing to ensure that Helen looks after herself too.

Outcomes

Robbie engaged with the support provided. He enjoyed the activities, and Small Steps were able to discuss topics such as school, friendships, anger and family relationships. Robbie does still have outbursts but Helen feels these have got better, and he is opening up more in his own way, such as writing messages on the kitchen blackboard. Helen is factoring in more quality time with him, such as film nights, swimming and trips out. She is feeling stronger and is arranging a meeting in school to review support for Robbie, as his 1:1 time

was reduced when the school SENCO changed. She wants to ensure that relevant support will be put in place for Robbie as he will soon be studying towards his GCSEs. In addition, Helen is seeking support from counselling for her own wellbeing, and is exploring support for Robbie to see if he will re-engage in order to explore potential issues around lack of positive male role models (and loss of two fathers), behaviour and self-esteem. Robbie has also agreed to attend some football coaching sessions following the support from Small Steps. Helen will continue to be part of the Small Steps Service through attendance at drop-ins for peer support, and will access a befriender to support wellbeing and reduce feelings of isolation.

*Names have been changed to protect anonymity

7. Process evaluation

7.1 Process summary

The services offered by Small Steps work well overall; the content is appropriate, the staff are effective and empathetic, and many parents compared Small Steps favourably with other services. Both families and professionals commented on how Small Steps is able to give more time to individual families, giving families a greater level of consistency in support and meaning that more progress is possible.

However, there are some significant challenges facing both Small Steps, and the overall Concerning Behaviours Pathway that Small Steps is part of. These challenges mean that Small Steps may not be creating as large an impact on families as it might, and that some families with more significant issues are experiencing delays in accessing higher levels of support.

The challenges have been grouped below into three overlapping areas:

- Challenges with communication
- Challenges with the referral process
- Other challenges with the new pathway

These issues may have arisen partly because of the challenge that the Small Steps team had in transitioning from a small pilot project to a much larger service. This process was undertaken at pace and may have affected Small Steps' ability to get the right systems and staff in place from the beginning. If these challenges could be overcome, then Small Steps would have the potential to create a lot of value for families in Nottinghamshire.

7.2 The need for the Small Steps Service

Partners were positive about the rationale for the Small Steps Service. Some spoke about other support that had been available for parents and carers in the past, but this was seen as harder to access and less consistent than Small Steps. For many, Small Steps fills a gap. In addition, the aim of reducing inappropriate referrals to paediatrician was supported by all of the partners who took part in the interviews.

“We were struggling with Tier 2 services - there was nothing in between Tier 1 and Tiers 3-4. So we were at a loss until Small Steps came along... for us having somewhere to go, not being left with

families in limbo, is fantastic... it's been a lifeline for me and the families I work with." [Partner - Public Health]

"I thought it sounded exactly like what the families we work with needed. We work with families who are on the path to diagnosis or who have been recently diagnosed or even before we were involved, but a common factor that runs through the work that I do with families is that often when we pick the cases up they say that they don't understand what ASD or ADHD is. They have just been diagnosed and given medication but a lot of them don't have any information about how their child might think differently to a sibling. I thought that having a service that can help with that specifically would be incredibly beneficial to the parent." [Partner - Early Help Team]

"[No other services] that offer such a broad range. You get specialisms of support but they are focused on specific diagnosis whereas Small Steps are much more general... The key difference is that Small Steps has drop ins which are wider ranging meaning that people can come and discuss a variety of issues which can actually help to limit paediatrician referrals as the families can support each other." [Partner - Early Help Team]

7.3 The Small Steps approach

Overall, partners felt it was too early to judge the impact of the Small Steps Service. Nonetheless, many had a view about the approach Small Steps were taking, the way it operated, and how this would create benefits for families. They pointed to the time that Small Steps were able to spend with families, the importance of giving children a supportive non-family member to talk to, and the importance of creating peer-support groups for parents. They also believed that the presence of Small Steps helped them make the case to parents that support for families affected by ASD and/or ADHD is important; diagnosis on its own is unlikely to be enough for them.

"Because of the large number of cases that we have, I can't spend that much time trying to engage the young person as I would like to [whereas Small Steps can]." [Partner – Early Help Team]

"Many parents do want to see a paediatrician, they want to know if [the] child needs a diagnosis. But what we say to parents is that we have this additional service that can support you – [the] paediatrician gives you [a] diagnosis, but what you need is support. If it's sold to a parent correctly it's a service that will work well." [Partner – Public Health]

"The key difference [compared to other services] is that Small Steps has drop ins which are wide ranging, meaning that people can come and discuss a variety of issues which can actually help to limit paediatrician referrals as the families can support each other." [Partner – Early Help Team]

"As far as I am aware people speak highly of their service and it seems that they are delivering a much-needed service." [Partner - Early Help Team]

"Overall, the Small Steps service on paper is very appropriate and provides good care to families pre and post diagnosis. The team work hard to ensure quality of care, including the specialist practitioners. The team is very amenable to change, and working together to improve the transition between services." [Partner – Paediatric services]

"[The Small Steps team member]'s nature is very approachable, I think his skills [are strong], but his [personal] qualities [are strong] as well. He could work with professionals but also work really well with young people... [He was] so passionate about wanting to help the child... I think that was

one of the hardest cases I've ever dealt with. Just really good at what he did, and persevered... In our role [unlike Small Steps], sometimes if a child doesn't engage after three times, we have such a high case load that... we'll try and try and try, but we're often bound by the rules... if they don't engage after three times then we strike them off case load, but that doesn't necessarily work with autism." [Partner – Early Help Team]

Parents and carers who accessed the service were also positive about the Small Steps approach, particularly the consistency that the service provided, and the time that the service was able to put into listening to families and their concerns.

"Someone listened well, when I felt there was no one else to hear me. They understood the issues my son is facing. They made every effort to offer support to all of the family." [Parent]

"It helps to speak to the same person so that they know you and your history and you don't have to start from the beginning every time. This has been so beneficial to me." [Parent / carer]

7.4 Communication

Some of the feedback on communication with the Small Steps team was very positive. Even when there were concerns about aspects of the communication, there was a consensus that the members of the Small Steps team were informative and helpful.

"The girls I've met [at Small Steps]... they're lovely, work really well with families. The calibre of staff will make it successful. The calibre of the staff they're employing is key." [Partner - Public Health]

"The direct contact I have had has been fabulous. If we can't answer anything then we've contacted them through email... recently I contacted Small Steps myself and the reception gave me all the details I needed, the difference between referral and drop in support. Very informative." [Partner - Early Help Team]

However, while the Small Steps team are seen as very helpful, many partners described issues with communication. There was a sense from partners that this was because the Small Steps team were struggling with capacity and the number of referrals they were receiving. However, many of the communication issues are about communication across the Concerning Behaviours Pathway, and the concerns raised are the responsibility of all agencies across the pathway, not just Small Steps.

Not all partners were aware of the change to the pathway initially. At least one Early Help team was not aware of the new referral process until they tried to refer through a GP, and found out (some time after the change had taken place) that the advice they had been giving was wrong.

"[The parent] completed the GTKY form that the parents had to take to the GP. This particular parent followed instruction that was suggested to her and she was initially told by her GP "yes that's fine, I'll make the paediatrician appointment' and then was called back a couple of hours later by the surgery receptionist and informed "we don't do paediatricians referrals any more, it has to go through Small Steps". So she phoned me and we were both confused – I thought I might have missed something – so I phoned Small Steps myself who explained that this had been the process since August and I called them in November." [Partner - Early Help Team]

“A new process has come in about referring through them, we were unaware for months, our paediatrician attended event but even wasn’t clear then that that’s the case. So caused a lot of delays – normally children would have already seen someone.” [Partner – Education]

There still appears to be some confusion among partners about the referral process. This includes confusion about whether GPs are able to refer directly to paediatricians without going through Small Steps (which they are in some cases: see Figure 3) and about who is responsible for the transition between the services. For example, in the quote below, a paediatrician believes that the Healthy Family Team (HFT) can offer support for children who require baseline anxiety work, but in the past has been directed to Small Steps.

“There is also some confusion between the healthy families teams and Small Steps about the transition between their services and also who sees which children which impacts on our service, e.g. who sees children who require some baseline anxiety work – we believe this is the HFT but they direct us to Small Steps.” [Partner – Paediatric services]

There are further issues with the understanding of the referral process which are discussed below, including the use of red flags to fast-track a family to paediatric support, and about services working together. This is an issue that the commissioners, as well as the services that are part of the Concerning Behaviours Pathway, will need to be aware of and continue the work already undertaken together to help others understand the pathway.

There are mismatches between how communication channels are meant to be used and how they are used in practice, which – alongside issues with capacity – is leading to further issues with communication between the Small Steps team and partners.

Partners reported that they often had to chase to get answers to emails; this was particularly important when it came to referrals. Small Steps’ referral email sends an automated reply to people telling them not to contact Small Steps on the email and to contact them via the support line; this process is not always followed by partners. Part of the underlying reason appears to be a mismatch between what partners expect Small Steps to provide, and what Small Steps believe is realistic given the level of resources and demand on the service.

“Recently I had a case I needed to escalate, but it took relentless phone calls before we [received feedback]. It was only when talking to [the support worker] when it became clear. The only reason it worked is because we pushed so much – we kept on calling until we got hold of someone... I presume there must be a waiting list, but I don’t know. Communication is not good – would expect them to get back to me.” [Partner – Education]

7.5 Challenges with the referral process

A major focus of the Small Steps service is the reduction of inappropriate referrals to paediatricians, and ensuring that those who are referred on to paediatricians are referred with all the necessary information for paediatricians to act on the referral.

It is not surprising therefore that the referral process was a point of discussion in interviews with partners. If Small Steps works with a family for a while before referring them to a paediatrician, that family will necessarily wait longer to see the paediatrician than if they had been referred directly – as might have

happened before Small Steps. Equally, if the service is successful then there will be a drop in the total number of referrals to paediatricians.

Partners were supportive of the changes that had been made to the Concerning Behaviours Pathway, and the intended role of Small Steps in the new pathway. Nonetheless, partners did raise some significant issues with the referral process, and especially the time taken for referrals to be processed and (where necessary) referred on to paediatricians.

There is a significant delay between a family being referred and the referral being acted on. This means that it is taking some families longer to access support than would have previously been the case. (Partners made this claim based on their own experience and their own data). This is a concern both to those doing the referring to Small Steps, and the organisations that Small Steps refers on to.

“I still have significant concerns about the waiting times for referrals into our service from Small Steps, and families accessing post diagnosis support after we have made a diagnosis. I am concerned about the impact this is having on the children and their families. We have had less than 10 referrals into our service via Small Steps since August 2018 [as of mid-April 2019]. Compared to previous referral rate of 50-70 children per month. These referrals have been appropriate and supported by appropriate information.” [Partner – Paediatric services]

“They probably do struggle with capacity at times, with the wider area that’s covered by the service. Numbers wise, with being a small service, the gap that they’ve been plugging is quite large, so it’s difficult from them capacity wise. There’s a huge need for this service.” [Partner – Public health]

Small Steps are aware of this issue; and have fed back that this is due to the volume of referrals they have received and their team’s capacity. The issue had already been raised with commissioners, and at the time of writing, the Small Steps team were in the process of putting a plan together to meet challenges around capacity.

The delay is particularly problematic for those with significant needs who are likely to need to be referred on to a paediatrician. There is a mechanism for partners to flag an individual case as particularly high need – by giving it a red flag, meaning that the referral goes to the GP for direct referral to a paediatrician, rather than via Small Steps. However, some partners appeared to be unaware of the mechanism, or may have believed that it only applied to children under five years old.⁸

Some partners believed that there was not a sufficient mechanism to fast-track referrals where, in the views of other professionals, a paediatrician will need to be involved, believing that, as Small Steps is now the only route for a family to be referred to a paediatrician, it may take longer for families with significant needs to access paediatric support. This may be through a lack of understanding of the red flag referral possibilities, or because the children they want to refer are above the age of five, or because the children in question don’t necessarily warrant a red flag but the partners believe they need to be fast tracked anyway.

⁸ The Concerning Behaviours Pathway diagram (in figure 3) could be interpreted as saying that Red Flags can only be used for children under the age of five.

The comments below illustrate some of the concerns of partners. Small Steps have responded to some of these points, and their responses are included after the quotes.

“We will need to have more referrals into our system to see if we are getting the right children or if we are just delaying their assessment by two years and they should have come to us sooner.”

[Partner - Paediatric service]

“We have had some concerns raised via the GPs and the healthy families teams about the delays, with referrals directed to our service stating that they are referring as the families have not heard from Small Steps or having been waiting a long time and have reached a crisis.” [Partner – Paediatric services].

“There are children that I’m really worried about, who are at risk of exclusion, extreme behaviour. I believe they need to see a paediatrician quickly.” [Partner – education].

“It’s gone too far the other way – it is now impossible to get a child in front of a paediatrician.”

[Partner – Education]

Partners can contact the Small Steps Information and Support Line to ask advice regarding a case prior to completing a referral to ensure the families go down the correct path. In addition, while paediatricians will prescribe medication or provide a diagnosis if needed, any support around behaviours (which may often be the priority) would still be provided by Small Steps.

The referral process can be time consuming. Some partners felt that it was disproportionately time consuming for those families that had lower levels of need. In addition, it can be particularly time consuming for schools to fill in the form when one of their students is exhibiting concerning behaviours at home rather than at school, and where they do not therefore have first-hand experience of the behaviours in question.

“Only thing was a bit of a stumbling block was referral. We do single assessment, but Small Steps is using the Getting To Know Me form so if the family doesn't have that completed then it's a large document for us to have to fill in when we have our own initial assessment form anyway... if you have a full assessment on a family which details everything, perhaps that could be shared?”

[Partner – Early Help Team]

“As a school, for a child that I’m not worried about, to have to do lots of paperwork for, is a bit annoying. I can see why - if you need to see a paediatrician or you're quite worried about [a child] or [a] parent [is] describing extreme behaviour at home, then it's useful to do a GTKM form, but if a parent is struggling a bit and just wants some advice, then it would be nice to have a short Small Steps referral form to refer them to a workshop... the Healthy Family referral form is really streamlined now... so sometimes I'm opting to refer to Healthy Family because it's easier than filling in a form for a child that I’m not worried about [while recognising that there may be genuine problems at home that parent is concerned with]... a Getting To Know Me Form can take me 25 minutes to do my bit, and 45 minutes to an hour when I count time with the parents.”

[Partner – education]

The design of the referral form is the responsibility of the County Council, and the form itself has been part of the Concerning Behaviours Pathway since before Small Steps was commissioned by the Local Authority. Small Steps need as much information as possible in the referral form so that families are allocated the correct support, and Small Steps also need evidence that the correct support has already been given before

the family is accepted. Small Steps and Commissioners continue to liaise about the format of the referral form based on feedback.

There have been some issues with feedback around the referral process. Some partners feel that they need to chase Small Steps to find out about the status of referrals they have put in.

“I have sent two referrals through – I received no acknowledgement if they’ve been received and what will happen next.” [Partner – Education]

“I’m not always sure why they get rejected.” [Partner – Education]

Overall, while having an organisation to refer to is a clear benefit to partners, the referral process itself is seen as problematic. Furthermore, while Small Steps may in the future create resource savings for paediatricians,⁹ at this point in time there appears to be an increase in volume of work for those referring in to Small Steps because of the Concerning Behaviours Pathway.¹⁰

7.6 Other challenges with the new pathway

There are some wider issues with the new pathway that have arisen, that go beyond communication and the referral process:

Joint working

One partner expressed concerns that they cannot provide support services to a family at the same time as Small Steps in the pathway, and that this might lead them to closing their case with a family – even when they had more to offer – in order to avoid further delays to paediatric support. This is illustrated in the comment below.

“Small Steps have said that if we’re in the middle of carrying out parenting or one-to-one work, they wouldn’t want to take the case on because the information that they give the child might be conflicting. I understand that, but if we make a referral to them and they say we won’t look at this until you have closed or are about to closed, that could be a couple of months down the line where that possible referral to the paediatrician is delayed by two months and given that paediatricians already have an enormous waiting list that could be a six months wait before that child is looked at. That concerned me and my colleagues – the risk to the young person is escalating while on waiting lists.” [Partner - Early Help Team]

Required attendance at Small Steps services

For the most part, both partners and families were very positive about the services attended by families:

“There’s not one family I’ve spoken to who have been unsure about Small Steps – they can see the long-term plan in place for them.” [Partner - Early Help Team]

However, there were some families that were attending Small Steps services because this was the only route for them to get the additional help they need. They did not believe they were getting much value from the Small Steps services themselves, but were attending because this was the only way to get a referral to a service that they believed was more appropriate to their needs (they may have been looking for a referral to

⁹ This could lead to significant resource savings. For example, the average UK cost to the NHS of a child attending a Paediatric consultant-led outpatient appointment is £201 (PSSRU, Unit Costs of Health and Social Care 2018), <https://kar.kent.ac.uk/70995/1/Unit%20Costs%202018%20-%20FINAL%20with%20bookmarks%20and%20covers%20%282%29.pdf>

¹⁰ This does not necessarily apply to paediatricians referring to the Small Steps Service for post-diagnosis support.

a paediatrician, or to a more structured service such as a workshop – particularly if they were currently attending a drop-in service).

“I was looking for a bit more structure – looking for more information. I can read about the condition online, but I was looking for someone who can give workshops on different topics. How to deal with things, what to expect. Today was better than the previous time I came – there was someone who met me at the door and told me about what would happen. But I’m still looking for more structure.” [Parent/carer]

“Deep down I can’t see the point in coming. Seems largely like red tape to me. While it’s nice to talk to people with similar experiences, I know what to do at home, how to distract him with bubbles or a bath if things are getting over the top. It’s nice to be able to be open with people, to talk to other people about it, but I’ll go home today and all I’ve had is someone else saying “my kid does the same”. The main thing I wanted – is help with his interaction. He doesn’t interact, e.g. if I show him a picture of a cat or a dog he doesn’t respond, and he doesn’t respond if I point to one in the street. So I can’t teach him anything. I need someone to show me different ways to get through to him. It feels like a really long way off to get what I really need for him. He’s already behind and it might be a long time before we get the support needed.” [Parent]

8. Case Study two: Leon

Leon* has a diagnosis of ASD and chromosome deletion which may impact his learning ability. Leon is a practical learner and enjoys subjects such as Science and Maths, but he can struggle with anxiety which impacts his ability to attend education. He has a positive relationship with his mum and siblings, but his condition can put a strain on the family.

Thanks to the support of the Small Steps Service, Leon’s mum, Enid, has benefited from an increase in self-esteem and confidence in implementing boundaries and guidance for Leon. She is better able to express her views in meetings and to other professionals, and she might even join the Small Steps volunteer programme to help empower other families facing similar situations. The Small Steps team supported the family with completing an Education Health and Care Plan for Leon. He is now engaging in home-based education and is attending alternative education. Furthermore, he is able to manage his anxiety better and go on public outings.

“I felt like I had someone to support me when I had no one else... I was at breaking point but now I am here to tell the tale.” – [Parent]

**names have been changed to protect anonymity*

7.7 Small Steps' Response to the issues raised in the Process evaluation

This chapter consists of Small Steps' response to the issues raised in sections 7.1 to 7.6 above.

The Small Steps Service recognises there are challenges with communication and referral processes, which in some cases are a result of the limited capacity of the service and the high number of referrals.

Communication

From our experience of implementing new services and pathways, it is to be expected that it takes some time for knowledge about what the service offers, and how to access the various levels of support to be embedded across various agencies. A variety of efforts have been made to communicate about the Concerning Behaviours Pathway and Small Steps Service, including attending events and team meetings, holding information sessions and sending out information bulletins. However, it is clear from the feedback of paediatricians and education partners that this communication needs to be ongoing. For example, Small Steps will work alongside other services to support families when needed, but depending on the need of the family, it may not be appropriate for more than one service to be involved. This is agreed on a case by case basis depending on what is appropriate for the child. This may be due to work required before a referral can be sent to Tier three services – Small Steps will not become involved until the outcomes of that initial work are seen, in order to know if that work has helped or if concerns remain. This enables the resources of the Small Steps Service to be focused in the right way. The service has sought to address confusion about what the service can offer and who it works with through the recent development of a 'Menu of Interventions' document, which summarises this. In addition, a Small Steps representative will continue to attend the steering group meetings for the Concerning Behaviours Pathway, which include all partners. The support line will continue to be available for queries from professionals and parents/carers.

The Information and Support Line also continues to be a popular method for staff at other agencies to ask the team for advice on what they should do in order to support a family they are working with, and this continues to be promoted on the automated emails people receive when sending a referral, or answerphone message where telephoning the office number. As the resources of the service are limited, it is felt that this is the best way to continue to communicate with other agencies, rather than allowing direct telephone calls to the office, as the volume of enquiries would limit the amount of direct delivery work able to be done by service staff.

To support parents to understand what the service can offer them, a 'welcome table' has now been set up for the first 30 minutes of a drop in session so that the group facilitator and volunteers can greet attendees and have a brief discussion about how the sessions work and what they aim to achieve. Every parent also has the opportunity to raise with the team that they feel they need further support by completing 'postcards'. The Small Steps team discuss what further support can be offered, or signpost the parent/carer to other services who can meet their needs.

Referral Processes

Some of the issues with referrals also relate to communication. The new Menu of Interventions document now clarifies the services that Small Steps offers, the target group for each of these and the referral process. It is apparent that some agencies are not aware that they can refer children over five directly to the Tier three services or other crisis services where there are red flags, leading to their concern that vulnerable families are not receiving support quickly enough. The service acknowledges that the wording of the

Pathway document (Figure 3) could have been misleading here. It is the intention that under fives with red flags are particularly concerning and thus are referred directly via GPs, but is not meant to indicate that over fives cannot be directly referred. If red flags are present (which do not include behavioural reasons), children should not be referred to Small Steps, and there should not be a delay to them receiving appropriate support. All partners of the Concerning Behaviours Pathway are currently discussing how red flags are communicated. If an inappropriate referral is sent to Small Steps, the professional who completed the referral will be sent a letter stating clearly why the referral has been declined, what the next steps should be and to contact the Small Steps Service if they wish to discuss the referral further.

It is the service's aim to reduce inappropriate or incomplete referrals to Tier three services, however the capacity of the service does mean that currently there is a delay around processing those referrals that should be made to Small Steps. The service is actively working on solutions to this. Families can access drop ins and the Information and Support Line at any time, including if they have been referred to Small Steps or Tier three services and are waiting for further support, so that families are never without support during the process.

9. Conclusions

The evaluation has shown that the Small Steps Service can have a major positive impact on families who have a child with ASD and/or ADHD. The service has created a number of outcomes for parents and carers in particular, and in some cases for children and wider family members. The core components of the service are strong: professionals and families speak highly of the Small Steps team, and the different service components.

The major issue for Small Steps is the volume of communications in general, and referrals in particular, that they have received. Small Steps does not currently have the capacity to process such a high number of referrals, and this has led to significant delays in accessing services for many families. In some cases this may have led to delays in accessing paediatric support, meaning that when families do finally get to see a paediatrician their problems may have worsened.

This has been compounded by wider issues around communication, in particular around the new referral routes. Some of these communication issues are the responsibility of Small Steps, but many are not. Some of these issues are likely to have been teething issues for the new Concerning Behaviours Pathway (which is only seven months old), but there remains some confusion among different services about exactly who can refer children to paediatricians. While the issue with capacity is not easily fixed, there is scope for improved communication across the Concerning Behaviours Pathway.

However, this is an issue that goes beyond Small Steps; much of the communication relies on people outside of the service, and significant efforts have already been made by the team to ensure that the new referral process and pathway is understood. These efforts include attending other services' meetings and providing the helpline – which is available for professionals as well as parents and carers.

It is clear from conversations with other stakeholders that Small Steps fills an important gap in provision – and delivers an important and necessary service. **It is the recommendation of the evaluators that the issues identified with capacity and communication need to be considered and reviewed within the context of a wider discussion about levels of demand how the pathway is working in general;** if these issues are addressed then Small Steps will have a very significant impact on families in Nottinghamshire.

"If they sorted [the referrals process] out, and a bit better communication, then it would be a really good service." [Partner - Education]

Appendix 1: Answers to closed questions parent/carer survey

The tables below set out the answers to the parent/carer survey, which was conducted in March 2019.

Figure 14: Approximately how long ago did you first start using the Small Steps Service?

	Number	Percentage
Up to 3 months	1	17%
3-6 months	3	50%
More than 6 months	1	17%
Not answered	1	17%

* When they filled in the survey

Figure 15: Do any of the following apply to you?

	Number	Percentage
I am the parent or carer of a child who has been diagnosed with autism	3	33%
I am the parent or carer of a child who I believe has autism but has not been diagnosed	1	11%
I am the parent or carer of a child who has been diagnosed with ADHD	2	22%
I am the parent or carer of a child who I believe has ADHD but has not been diagnosed	3	33%
I am the parent or carer of a child with other conditions similar to autism or ADHD	0	-
None of these	0	-

* Respondents were asked to tick all that applied

Figure 16: Age of child with autism, ADHD or a similar condition

	Number	Percentage
3-5	1	20%
6-8	1	20%
9-11	1	20%
12-14	2	40%

Figure 17: Which of the following activities of the Small Steps Service have you taken part in?

	Number	Percentage
Attended the four-week workshop course	3	14%
Attended drop-in group for parents	2	9%
Called the Information and Support Line	3	14%
Received one-to-one support from a Small Steps support worker	6	27%
Had meetings with your child's school where a Small Steps support worker has attended	4	18%
Had meetings with health or social care services where a Small Steps support worker has attended	1	5%
Had meetings with other types of services where a Small Steps support worker has attended	1	5%
Received help and support from a volunteer befriender	0	0%
Been referred on to other services by Small Steps	2	9%

* Respondents were asked to tick all that applied

Figure 18: Thinking about your experience of the Small Steps Service, how would you rate the following aspects of the service?

	Excellent	Good	Fair	Poor	Very poor	Don't know
The four-week workshop course	4	-	-	-	-	-
The drop-in group for parents	1	1	-	-	-	1
The Information and Support Line	3	1	-	-	-	-
The one-to-one support from a Small Steps support worker	4	1	-	-	-	-
Support from a Small Steps support worker at a meeting with your child's school, health or social care services, or with other types of services	3	1	-	-	-	1
Help and support from a volunteer befriender	-	-	-	-	-	1
Communication between the service and families	3	1	-	-	-	-
The way in which Small Steps works with other services (e.g. schools, GPs, paediatricians)	1	1	-	-	-	1
The speed with which referrals to Small Steps are processed	1	2	-	1	-	-

* Respondents were asked to ignore aspects of the service that they had not taken part in.

Figure 19: What do you think are the most important things about the Small Steps Service?

	Number of responses	Percentage of responses
The Small Steps team are non-judgemental, understanding and caring	6	15%
The Small Steps team have appropriate experience, skills and knowledge	5	13%
There are frequent opportunities to meet with members of the Small Steps team face-to-face	4	10%
There are a variety of different ways to contact and get support from the Small Steps team	4	10%
There are frequent opportunities to meet with other parents/carers with children with autism and/or ADHD	4	10%
Meetings are accessible in terms of location, timing, day of the week	4	10%
The Small Steps team have sufficient time to spend with families	3	8%
The Small Steps team can speak up on behalf of families when issues arise at school or with other services	3	8%
High-quality training for family members is provided as part of the service	3	8%
Different strands of the service work well together (e.g. drop-in groups, workshops, the Information and Support Line)	2	5%
There is enough involvement of different stakeholders (such as schools, GPs, paediatricians, other charities)	2	5%
Total	40	100%

* Respondents were asked to select maximum five options.

Figure 20: Please think about the impact of the Small Steps service on you. Please look at the statements below, and indicate how much you agree or disagree with each one.

	Parent					
	Strongly agree	Somewhat agree	Neither agree nor disagree	Somewhat disagree	Strongly disagree	Don't know
I have a better understanding of my child /children's behaviour	3	-	2	1	-	-
I am better able to manage the behaviour of my child/children	1	2	2	1	-	-
I feel more confident about my parenting ability	1	2	1	2	-	-
I am more aware of local provision for families affected by autism and/or ADHD	2	1	2	1	-	-
The support that I get from my child's school has improved	1	-	2	3	-	-
My child/children is getting more appropriate support from other services	1	-	2	2	1	-
My relationship with my child/children has improved	1	1	1	2	1	-
My relationship with other family members has improved	-	-	3	2	-	1
I feel more positive about myself	1	2	-	1	1	1
I feel less isolated	2	1	-	2	1	-
I am better able to stay calm when things go wrong	2	1	2	1	-	-
My own mental health and/or well-being has improved	1	2	-	1	1	1

Appendix 2: Answers to open questions and comments parent/carer survey

<p>What, if anything, do you think is particularly good about the Small Steps Service?</p>	<ul style="list-style-type: none"> • Someone listened well, when I felt there was no one else to hear me. They understood the issues my son is facing. They made every effort to offer support to all of the family. • Empathy. Kind, caring, supportive staff. Personalised advice (not textbook). Go out of their way to find you advice/support. • It gives me a better understanding of ADHD. • I think Small Steps is good but maybe could have done with this 3/4 years ago. • I was long [alone?] then four week. Could do with some more help. • Support. Having someone to talk to, to know you're not alone. Very friendly and open.
<p>What, if anything, do you think could be improved about the Small Steps Service?</p>	<ul style="list-style-type: none"> • To remain with families longer, even when they feel they have nothing left to offer. The family may rely on the contact and feel lost without it. • Longer advice line hours. • Having someone going into school could last longer. • More funding for them so they can help and support more families.
<p>If you have any comments or examples you can share related to the above question [experience of the Small Steps Service], please give them here.</p>	<ul style="list-style-type: none"> • [The support worker] provided excellent support to my family and worked hard to 'work together' with school and SENCO. • Referral help up... Kept going back and forward. • It was longer than four weeks. And she was excellent with us helped so much.
<p>If you have any comments or examples you can share related to the above question [important things about the service], please give them here.</p>	<ul style="list-style-type: none"> • It helps to speak to the same person so that they know you and your history and you don't have to start from the beginning every time. This has been so beneficial to me. • I need more help • They have first-hand experience of children with ADHD/autism.
<p>Please think about the impact of the Small Steps Service on your child / children with autism and/or ADHD. How, if at all, have your children been affected by the Small Steps Service?</p>	<ul style="list-style-type: none"> • My son is not cooperative at present. This is not the fault of the service providers, it is just the stage that 'we' are in. However, I have relied heavily on the service and appreciated every aspect of the support offered. • My granddaughter got on so well with the person from Small Steps on visits to school. She opened up to him. • [Small Steps team have] not met my son so he's just the same. • I would like Small Steps to work with myself and my son for more weeks. We need the help.
<p>If you have any final comments on this survey or on the Small Steps Service, please give them here.</p>	<ul style="list-style-type: none"> • I wish that the support was not coming to an end, but I do understand why it is. However, from the autistic viewpoint, change is never welcome therefore it will be difficult to accept. • I would like to highlight [the support worker] from the workshops. She has been an amazing support... Checking in regularly and offering to help further with sleep by using me as a case study. I feel less isolated and out of control and her professionalism and care have been vital for me. • I would have liked more time with Small Steps. It finished too soon. • I think Small Steps is a good service but maybe for the start of people's concerns and diagnosis. • Very helpful. • Small Steps are a big support to me and my son. They have given me the confidence to deal with school and so many ideas on how to deal with my son on a day to day basis.